



TOM CILMI
Suffolk County Legislator
10th District

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Histiocytosis Day - January 26th



Legislator Cilmi is shown with Taylor Ryan at the Taylor's Hope Foundation 2nd Annual Blue Ribbon Dinner

Back in late 2013, Legislator Cilmi (R-East Islip) sponsored legislation that declared January 26 Histiocytosis Day in Suffolk County, with hopes to generate awareness for those, like Taylor Ryan, who suffer from Langerhans Cell Histiocytosis.

Langerhans Cell Histiocytosis is a rare debilitating neurodegenerative disease which effects 1 in 200,000 children.

Taylor has a lesion on her brain from the histiocytosis, and suffers from a number of related symptoms including diabetes insipidus, seizures, weakness on one side of her body, blurred vision, headaches and some difficulty with comprehension. She has gone through years of chemotherapy, numerous surgeries and a variety of other procedures.

To increase awareness, the family started the Taylor's Hope Foundation. The Foundation holds two major fundraising events a year: the Blue Ribbon Dinner held this year on January 10th and "Bowling for Histio" held in July. The Ryan's also sponsor a Holiday Toy Drive, which this year collected over 750 toys, distributed to homeless children through MSG's Garden of Dreams Foundation as well as through Cohen's Children's Hospital.

"When I first met the Ryan family, Taylor was a little girl going through more than any little girl should have to go through, but doing so with remarkable grace and optimism, Taylor's grown quite a bit in the last six years, but she is still very much a child. Yet, with a smile a mile wide, her strength and positive attitude are truly remarkable. She continues to be such an inspiration to the entire community. Her spirit and energy are infectious and her generosity is a blessing to others. She a champion in every sense," said Cilmi.

Cilmi also had high praise for Taylor's family. "Her mom and dad are pillars of strength, and I can't say enough about her younger sister Samantha who, in some ways, lives in Taylor's shadow, but finds a way to shine in her own right as bright as the sun."

Those interested in learning more about Taylor or LCH can find more information at www.taylorshopefoundation.com.

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